



Title: Learning Disabilities Briefing Paper

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Cabinet Member sign-off: Cllr Mike Appleyard

Purpose of the agenda item:

This paper provides Members with an overview of Learning Disabilities within a national and local context. It highlights forecasted demand for local services and provides details of the service's current work streams.

1. The National Picture for Learning Disabilities

National Population of People with Learning Disabilities

Data gathered from a number of sources by Public Health England, at the Learning Disabilities Observatory, estimates that in England in 2012 there were an estimated 1.14million people with learning disabilities; 232,000 under the age of 18yrs and 908,000 adults had learning disabilities of which 21% are known to learning disability services.¹

National Drivers

Nationally published reports and guidance over the last decade reinforce the need for integrated services shaped around people with learning disabilities and their families; greater service user involvement; services that deliver early interventions and promote wellbeing and services that focus on outcomes for individuals. Policy and reports continue to challenge current thinking and make clear the significant shifts in culture that need to be made.

Appendix 2- Provides details of national drivers, key messages and links

¹ [People with Learning Disabilities in England 2012: Improving Health and Lives](#)

National Context

There are a number of key health and social issues for people with learning disabilities.

i) Health inequalities:

Higher mental health needs² - the prevalence of psychiatric disorders among children with learning disabilities is 36%, compared to 8% among children without learning disabilities.

Co-existing autism spectrum disorders³ - the prevalence of autism has been reported to be as high as 20-30% in people with learning disabilities known to services.

Challenging behaviours⁴ - studies show that approximately 10 -15% of people with a learning disability present with behaviours that challenge services. These behaviours may include self-injurious behaviour, aggression toward others and destruction of property.

Physical ill health - people with learning disabilities still have an increased risk of early death compared to the general population⁵; although the life expectancy of this population is increasing over time. People with learning disabilities have reduced access to generic preventative screening and health promotion procedures, such as breast or cervical screening.

ii) Social inclusion and opportunities⁶:

Employment - less than 1 in 5 people with a learning disability work (compared with 1 in 2 disabled people generally). Of those people with a learning disability that do work, most only work part time and are low paid.

Education and training - just 1 in 3 people with a learning disability take part in some form of education or training.

Bullying - children with a learning disability are often socially excluded and 8 out of 10 children with a learning disability are bullied.

Poverty - 1 in 2 families with a disabled child live in poverty.

Independence – people with learning disabilities don't get the same chances as other people to gain independence, learn key skills and make choices about their own lives.

Carers support - 7 out of 10 families caring for someone with profound and multiple learning disabilities have reached or come close to 'breaking point' because of a lack of short break services

In addition, people with learning disabilities, especially those with less severe disabilities who do not use learning disability services, are more likely to be exposed to common “social determinants” of health such as poverty, poor housing conditions, unemployment and social disconnectedness.

² Emerson, E.Baines, S. Allerton, L. and Welch, V. (2011) A detailed analysis of the health inequalities suffered by PWLD is available at: [Health Inequalities & People with Learning Disabilities in the UK.](#)

³ [Guidance for commissioners of mental health services for people with learning disabilities \(May 2013\) Joint Commissioning Panel for Mental Health](#)

⁴ Emerson, E (2001, 2nd Edition) Challenging Behaviour, Analysis and intervention in people with learning disabilities.

⁵ Source: Hollins et al., 1998; McGuigan et al., 1995

⁶ [Mencap facts about learning disabilities](#)

2. Buckinghamshire Picture for Learning Disabilities

At the last census (2011) Buckinghamshire had a population of 505,280 and an estimated 5890 (18-65) and 1370 (over 65yrs) adults with a learning disability⁷.

In line with the general population figures for Buckinghamshire, of the people with learning disabilities:

- 37% live in Aylesbury Vale
- 33% live in Wycombe
- 17% in Chiltern
- 13% in South Bucks

Local Context and Services

The learning disability social care service for Buckinghamshire is made up of two area based care management teams, responsible for the assessment of needs of individuals and their carers. In addition a small team are responsible for the assessment and support planning for those transitioning into adulthood.

Currently the number of adults aged 18yrs+ with learning disabilities, assessed as eligible and in receipt of services from the local authority in Buckinghamshire are around 1000. This number has remained relatively consistent over the last 5 years.

Individuals are in receipt of a range of care/support packages including supported accommodation, day services, supported employment, and domiciliary care.

Costs for services for people with learning disabilities increase in relation to assessed needs and for some the packages of care may be high due to very complex support needs.

Appendix 3 – details a pictogram of costings against social care need

Where there are health needs these will be met through health funding streams. For a small number of individuals who may have behaviours that challenge, support will be intensive and specialist at times and may require either short periods of time in specialist hospital settings or long term placements with specialist providers, either in county or out of area. Currently this funding is in excess of £8million (including Continuing Health Care).

Specialist learning disability health services in Buckinghamshire are currently provided by Southern Health Foundation Trust. This service is commissioned and funded by the Chiltern Clinical Commissioning Group; the total budget for this service is £3.4million and provides specialist community assessments and interventions as well as inpatient beds at an assessment and treatment unit in Wycombe. Individuals

⁷ Population statistics for Buckinghamshire – ONS 2011 (BCC, 2013)

Future demand

Estimated projections regarding the population of adults with learning disabilities in Buckinghamshire have been sourced through Planning4Care⁸

The overall number of people with learning disabilities aged 18-64yrs is projected to decrease, whilst the number of people with profound and multiple learning disabilities is projected to increase (table1).

	2011	2021	2031	% Change 2011-2031	
				Buckinghamshire	England
PMLD	150	169	199	30%	44%
SLD	1130	1101	1077	4.5%	7%
MLD	4610	4498	4356	5%	5.5%
Total	5890	5768	5631	4%	6.5%

Table 1: Estimated projections for number of adults with learning disabilities (by severity) aged 18-64yrs, in Buckinghamshire. Source Planning4Care 2010

The population of older people (65yrs+) with learning disabilities in Buckinghamshire, is projected to increase over the next 20years (table 2).

	2011	2021	2031	%change 2011-2031	
				Buckinghamshire	England
PMLD	20	30	40	100%	102%
SLD	160	190	240	50%	50%
MLD	1190	1500	1840	55%	49 %
Total	1370	1720	2120	55%	50 %

Table2: Estimated projections for number of adults with learning disabilities (by severity) aged 65yrs and over, in Buckinghamshire. Source Planning4Care 2010

Both older people with learning disabilities and those with profound and multiple difficulties will require complex long term case management support.

Appendix 4 – details a pictogram showing changes in demographics from 2011 to 2031.

Transforming Care (Winterbourne Concordat)

In line with the requirements of NHS England Transforming Care policies and guidance commissioners have a robust programme of reviews for all Buckinghamshire people with a learning disability in hospital placements. All those inappropriately placed are supported to move back to community based support where possible. In addition:

- A local register has been maintained since 2013
- All individuals have a named case manager/care coordinator
- The joint commissioner works with a senior care manager and a senior LD community nurse; meeting weekly and chairing the care and treatment reviews of all those on the register
- Reports regarding the register and progress with discharge planning is made fortnightly to the NHS regional team and then monthly to HSCIC
- All those placed in hospital settings have access to independent advocacy and where appropriate their families are involved with planning

⁸ Source Planning4Care estimates 2010

- All care and treatment reviews are chaired by the joint commissioner (or the delegated case manager) and include an independently assigned clinical reviewer and an independent expert by experience, identified and supported by the NHS England team
- Care and treatment reviews provide a challenge to hospital placements and ensure that discharge plans are robust and appropriate

Of those who are the responsibility of Buckinghamshire Clinical Commissioning Groups there are currently (as of September 2015):

- 5 individuals who have been placed (and funded) by NHS England Specialist Commissioning, in low/medium/high secure services out of the county. Decisions about discharge are the responsibility of the Ministry of Justice.
- There are 3 individuals who are currently in specialist inpatient services out of the county; all of which are currently appropriately placed and are reviewed regularly
- There are 4 individuals currently in the local assessment and treatment unit (at High Wycombe)

Learning Disability Work Programme

A number of work programmes are underway within the learning disability services. The key areas of work to note are set out in Appendix 1 overleaf, with a summary of some of the outcomes and measures being worked towards.

<p>To develop a better understanding of social care LD capacity and demand in relation to both:</p> <ul style="list-style-type: none"> i. staffing and budgets and MTP effects ii. budgets and MTP effects 	<p>Sep 15</p>	<p>3 year rolling understanding of LD capacity and demand, translated into a budget requirement for staffing and budgets</p>	<p>A 3 year rolling plan of new demographic growth for new transitions</p> <p>Number of new young people transitioning into adult services for the next 3 years.</p> <p>Leadership paper and Business plan (if appropriate) for LD social care staffing capacity</p>
<p>LD Accommodation review</p>	<p>March 2016</p>	<p>An annually updated Housing Strategy for vulnerable adults in Buckinghamshire</p> <p>A financially sustainable model of housing services for people with learning disabilities in Buckinghamshire</p> <p>A clear understanding of demand aligned with new and existing accommodation capacity ensuring people with a learning disability are appropriately housed and supported</p>	<p>Development of robust data to understand:</p> <ul style="list-style-type: none"> - housing types - Support needs - Future housing needs for people with learning disabilities, including demands for moving <p>Project Initiation Document (PID) Project Plan</p>
<p>Developing a “local offer” for people with learning disabilities continuing to live at home with parents into adulthood</p>	<p>April 16</p>	<p>A range of services are available to support parents and people with a learning disability who live with them</p> <p>A “local offer” exists and is clearly communicated to individuals and their families</p>	<p>Development of robust data to understand the profile of service users living with families, including:</p> <ul style="list-style-type: none"> - Ages - Support needs now and in the future - Accommodation needs
<p>Transition Services – improving the experience of young people and their families in the transition from children’s to adult services (across all disabilities)</p>	<p>Ongoing 2015-2017</p>	<p>A fully recruited, highly skilled transitions team is in place to assess and support young people and their families</p> <p>Carers and service user surveys report high levels of satisfaction and a good experience of the transition process</p> <p>A clear transitions pathway is in place supported by a transitions protocol</p>	<p>Quality outcomes are developed and reported in relation to service delivery</p> <p>Strategic Transitions Board develops action plan reflecting areas for implementation and improvement</p> <p>Carer and service user engagement developed to understand areas of improvement</p> <p>Reduction in number of complaints</p>

		Services and protocols are monitored by a board with joint health and social care scrutiny and ownership across children and adult services	
Autism Strategy for Buckinghamshire	Ongoing 2015-2018	Seamless all age diagnostic, assessment and support services for individuals and their families affected by autism.	Key Measures for 2015: <ul style="list-style-type: none"> - Autism Partnership Board represented by adult and childrens services; across health and social care - Embedding of diagnostic and assessment pathway for adults affected by autism; aligned with children's pathway - Mapping of support services for adults affected by autism in Buckinghamshire - Deliver autism awareness training programme across criminal justice system, social care and health staff - Develop Autism resource website
Staying Healthy – In line with annually submitted LD Health & Social Care Self Assessment to Public Health England	Ongoing	People with learning disabilities have their healthcare needs met through improved access to primary care services whenever possible	Working group action plan developed , key measures for 2015: <ul style="list-style-type: none"> - Increase in the number people with learning disabilities having an annual health check - Improved access to health screening - GPs have access to Information and guidance - Raised awareness of the LD liaison nurses - Flagging system established for acute and secondary health services - Improved data regarding the health of people with learning disabilities is made available (including those in criminal justice system)
Keeping Safe – In line with annually submitted LD Health & Social Care Self Assessment to Public Health England	Ongoing	High standards are maintained in relation to safeguarding and quality of commissioned services Individuals and their carers provide positive responses in relation to dignity and care in the services received Individuals are safe from crime, intolerance and	Key measures for 2015: A full schedule of annual reviews are in place People with learning disabilities are active members of the safeguarding forum Promotion of Community Safety initiatives:

		discrimination	<ul style="list-style-type: none"> - The Safe Place Scheme - Hatecrime - Anti - Bullying - Disability awareness training <p>Surveys to carers and service users reflect an increase in % feeling safe</p>
Living Well – In line with annually submitted LD Health & Social Care Self Assessment to Public Health England	Ongoing	<p>Communities are socially inclusive and people with learning disabilities have access to a broad range of reasonably adjusted facilities, amenities services and opportunities including:</p> <ul style="list-style-type: none"> - Work; support to enter and maintain employment - Leisure activities; cinema, theatre, music venues etc - sports facilities - changing places - Public transport <p>Information is widely shared and accessible</p>	<p>Key measures for 2015:</p> <ul style="list-style-type: none"> - Mapping of universal services having reasonable adjustments to allow access by people with learning disabilities - Service user and carer views to be provided to transport providers
Service user engagement	Ongoing	<p>Adults with a learning disability are enabled to participate in decisions and actions that affect their lives.</p> <p>The experience and knowledge of service users contributes to the design, planning, evaluation and delivery of services</p> <p>Accessible formats for information are available to adults with a learning disability</p> <p>People are involved in their own support planning and/or where appropriate the development of the service itself</p>	<p>Key measures for 2015:</p> <ul style="list-style-type: none"> - Commissioning of service for the engagement with people with learning disabilities including those transitioning to adulthood - Review of the Learning Disability Partnership Board to improve effectiveness - Key areas of focus for LDPB and action plan developed

		<p>Service improvements are evidenced through service user engagement and involvement</p> <p>There is a range of innovative ways of involving and engaging with service users and their families are in place</p>	
Commissioning Strategies	March 2016	<p>Our Joint Commissioning Strategy is the formal statement for future plans for services for people with learning disabilities in Buckinghamshire</p> <p>Our Joint Commissioning Strategy is the formal statement for future plans for services for people with autism in Buckinghamshire</p> <p>Our Joint Commissioning Strategies have been informed by National Policy and best practice and the views of people with learning disabilities and/or Autism and their carers/families as appropriate)</p> <p>Our Joint Commissioning Strategies cover social care services/support, specialist and universal health services and preventative services</p>	<p>Key measures for 2015:</p> <ul style="list-style-type: none"> - Development of draft Joint Commissioning Strategy for Learning Disabilities - Refresh the Joint Commissioning Strategy for Autism - Establish a Learning Disability Providers' Forum - Engagement with learning disability groups and carers

Appendix 2

Key National Drivers

Valuing People (2001) and subsequently Valuing People Now (2009) [here](#)

Valuing People continues to be the cornerstone of services for people with learning disabilities. Key messages:

- **Rights:** People with learning disabilities and their families have the same human rights as everyone else.
- **Independent living:** People with learning disabilities should have greater choice and control over the support they need to go about their daily lives; greater access to health, housing, education, employment, leisure and transport opportunities and to participation in family and community life.
- **Control:** People with learning disabilities should be involved in and in control of decisions made about their lives. They should have the appropriate information and support to understand the different options and their implications and consequences, in order to make informed decisions about their own lives.
- **Inclusion:** People with learning disabilities should be able to participate in all the aspects of community life – to work, learn, get about, meet people, be part of social networks and access goods and services – and have the support to do so.
- Support where required must be centred on the needs and aspirations of the individual, taking into account who the person is in the context of their friends and family, who are most important to them and ensuring that the quality and safety of the support enables people to feel safe and enjoy positive experiences.

In addition:

- Good Health - enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary.
- Partnership working - to promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

The Future role of psychiatrists working with people with learning disability, Royal College of Psychiatrists, 2011 [here](#)

“A tiered approach based on a stepped care model with care pathways is the most efficient way of commissioning specialist health services for people with learning disability. We recommend that health commissioners and providers adopt such a tiered approach suitably modified to take into account the local circumstances. The implementation of such a model should enable the psychiatrists who work with people with learning disability to deliver the services in an effective way which provides the best value to service users.”

Think Local Act Personal (TLAP) – Be Bold 2012 [here](#)

This report produced by the NDTi is intended to help commissioners, adult social care and their health partners, providers, and people who use services and their families to work together. It provides a framework in which to develop good working practices that are innovative and help shape individualised services that increase choice and control.

Transforming care: A national response to Winterbourne View Hospital: Department of Health Review Final Report 2012 [here](#)

This report lays out clear, timetabled actions for health and local authority commissioners working together to transform care and support for people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging and emphasises there are too many people with challenging behaviour living in inpatient services for assessment and treatment and they are staying there for too long.

The report recommends a 'model of care' with clear outcomes and sets out a range of national actions which the Department of Health and its partners will deliver to lead a redesign in care and support for people with learning disabilities or autism and mental health conditions or behaviours viewed as challenging.

The green light is a toolkit (Closing the Gap: priorities for essential changes in mental health services) [here](#)

Green Light Toolkit 2013 NDTi; A guide to auditing and improving your mental health services so that it is effective in supporting people with autism and people with learning disabilities (November 2013) [here](#)

Key resources in improving mental health support services for people with learning disabilities. Painting a picture of what good mental health support services for people with learning disabilities look like, and gives a way of assessing how well local services measure up to it and what actions can be taken to improve access.

People with learning disability and mental health, behavioural or forensic problems: The role of in-patient services, Royal College of Psychiatrists, 2013 [here](#)

This report provides a number of recommendations and sets out national actions to deliver five goals, namely: more people with learning disability being supported to live at home; fewer people developing behaviour that challenged and those that did being kept safe in their communities; far fewer being sent away to hospitals; and proper planning, keeping such hospital stays as short as possible.

"There should be an ongoing dialogue at a local level between learning disability health providers, mental health providers and local authorities to ensure that responsive local authorities and mental health services can help reduce the need for admission and shorten the length of stay in hospital. Commissioners and providers should plan from day one of admission to in-patient services for the person with learning disability to move back to community services."

Confidential Inquiry into Premature Deaths of people with learning disabilities (July 2013) [here](#)

This report makes a number of recommendations to improve the health outcomes for people with learning disabilities and it confirms:

"the substantial health care needs of people with learning disabilities too often go unmet as they can experience both avoidable illness and die prematurely, with symptoms not recognised by either the person or their family or carer leading to late diagnosis and treatment, too low expectations of the treatment they can expect and the therapeutic environment being too often unsuitable with a lack of reasonable adaptations."

Six Lives: Progress Report on healthcare for people with Learning Disabilities (2013) [here](#)

Ensuring Quality Services: core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges (Feb 2014). [here](#)

This document provides a detailed pathway and specification and is part of the Winterbourne View Joint Improvement Programme led by the LGA and NHS England. Its vision states:

“Everyone, with no exception, deserves a place to call home. Person by person, area by area, the number of people with learning disabilities and autism in secure hospitals or assessment and treatment settings will permanently reduce. At the same time local community-based support and early intervention will improve to the point it will become extremely rare for a person to be excluded from the right to live their life outside of a hospital setting”.

Strengthening the Commitment: one year on progress report on the UK modernising learning disability nursing review (May 2014) [here](#)

Key messages include:

- Maximise the contribution of learning disabilities nursing - ensure the knowledge and skills of learning disabilities nurses are provided to the right people, in the right places, and at the right time in a way that reflects the values and rights based focus of learning disabilities nurses' work.
- Addressing health needs - ensure that learning disabilities nurses are able to collaborate effectively with general health services, including mental health services, to address the barriers that exist for people with learning disabilities to improve their health. This should include proactive health improvement, prevention, whole family and public health approaches.

Healthy Lives, healthy People: Improving outcomes and supporting transparency Premature Deaths of people with Learning Disabilities: progress report (Sept 2014) [here](#)

Winterbourne View – Time for Change: Transforming the commissioning of services for people with learning disabilities and/or autism (2014) [here](#)

“The importance of building capacity in the community in order to successfully prevent people with learning disabilities and/or autism and challenging behaviour needing to be admitted to inpatient settings, and discharge those currently in hospitals. Without the expansion and improvement in quality [of community based support] people will continue to have crisis and be admitted to inpatient institutions, and many people with learning disabilities and/or their families, clinicians and commissioners, will continue to be nervous about discharge from hospital into the community”.

Positive and Proactive Care – reducing the need for restrictive interventions, DH, 2014. [here](#)

In response to Winterbourne View, concerns about the inappropriate use of restrictive interventions across a wide range of health and care settings and the development of guidance framework. The report provides key actions set against leadership, assurance and accountability, transparency and monitoring and oversight and makes recommendations which include the use of Positive Behavioural Support; individualised approaches; recovery-based approaches; whole service approaches.

Transforming Care for People with Learning Disabilities – Next Steps (Jan 2015) [here](#)

This latest report sets the programme of work going forward, including the early actions for 2015 in ensuring that people are “getting the right care in the right place”. Key themes are in building capacity in communities to reduce the need for hospital admissions and to ensure people who are admitted are discharged into a community setting as soon as possible. There is a strong emphasis on personalised care and support planning and the clear message of joint working between health and social care.

Supporting People with a Learning Disability and/or Autism who have a Mental Health Condition or Display Behaviour that Challenges (draft service model for commissioners of health and social care services (July 2015) [here](#)

In July 2015 NHS England, the Local Government Association (LGA), and the Association of Directors of Adult Social Services (ADASS) published a new draft national framework designed to improve the care of people with learning disabilities, shifting services away from hospital care and towards community-based settings.

The Service Model sets out nine overarching principles which define what ‘good’ services for people with learning disabilities and/or autism whose behaviour challenges should look like.

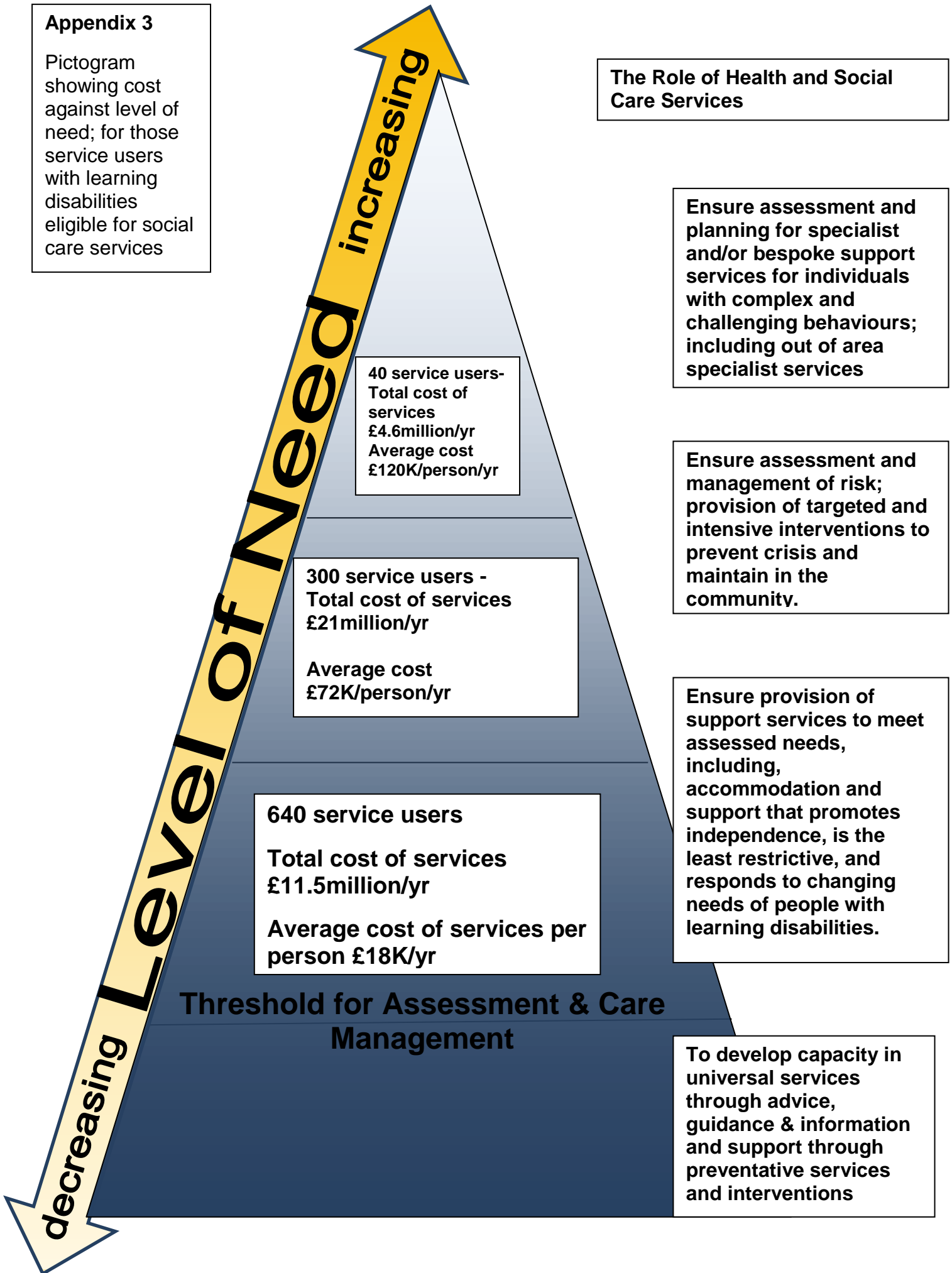
These principles will underpin how local services are redesigned over the coming months and years – allowing for local innovation and differing local needs and circumstances, while ensuring consistency in terms of what patients and their families should be able to expect from local decision-makers.

It is currently being tested by the five ‘fast track’ areas, which will use it to inform their transformation plans over the summer of 2015, and test it against the reality on the ground. NHS England, the LGA and ADASS will refine the guidance in response to any feedback and publish later this year.

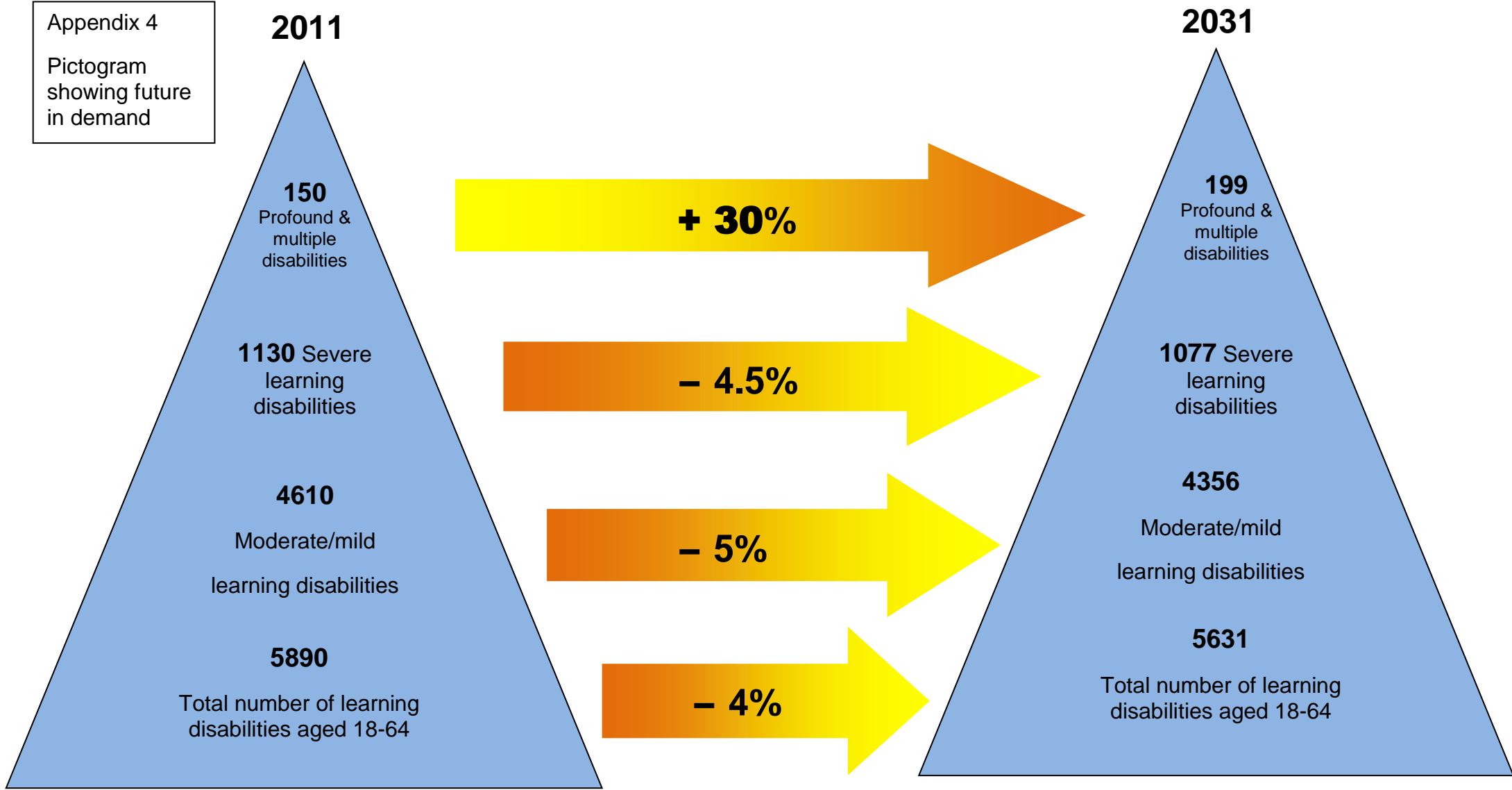
Appendix 3

Pictogram showing cost against level of need; for those service users with learning disabilities eligible for social care services

The Role of Health and Social Care Services



Appendix 4
Pictogram showing future in demand

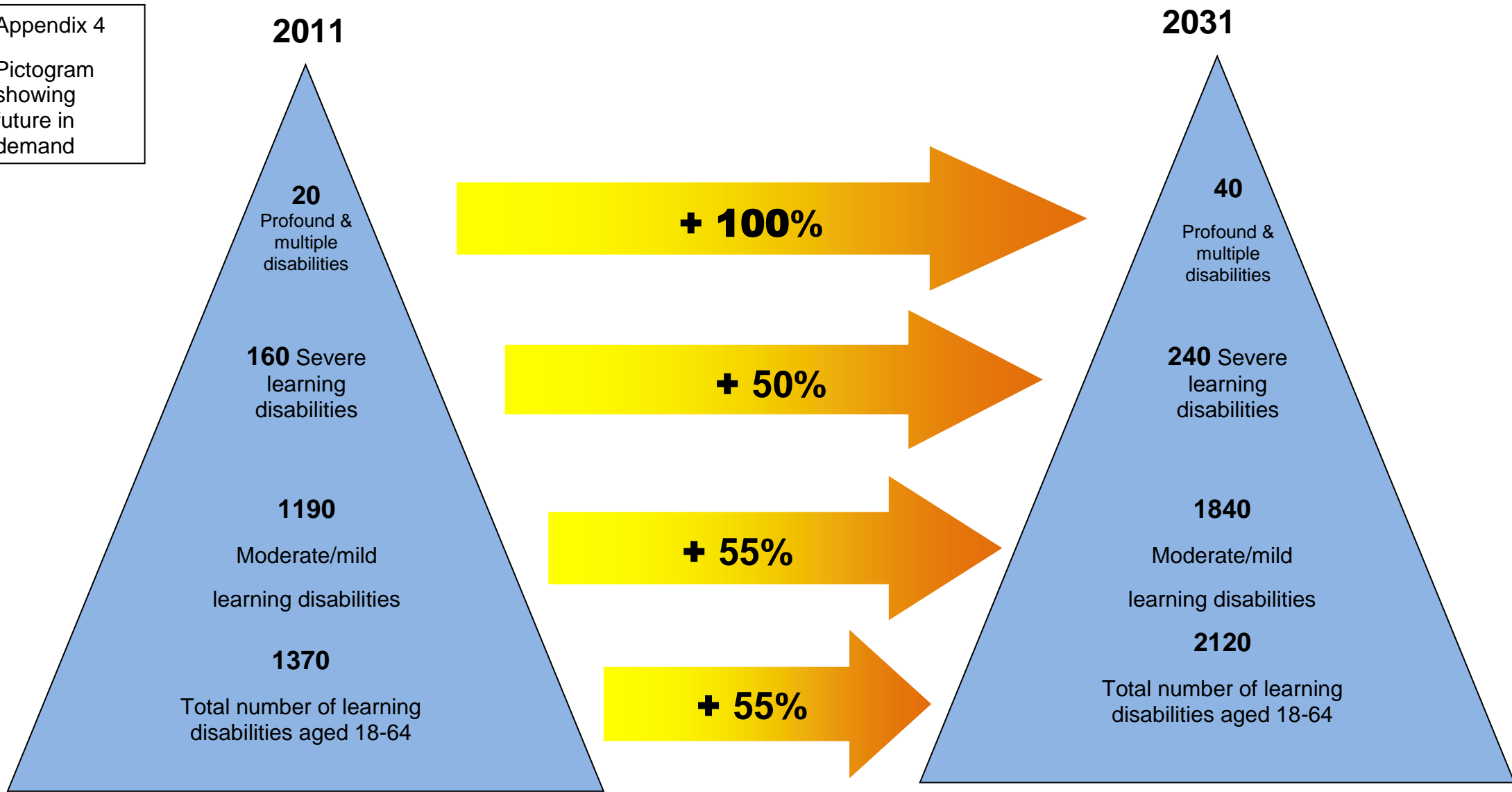


Estimated projections for number of adults with learning disabilities (by severity) aged 18-64yrs, in Buckinghamshire.

Source Planning4Care

The overall number of people with learning disabilities aged 18-64yrs is projected to decrease, whilst the number of people with profound and multiple learning disabilities is projected to increase.

Appendix 4
Pictogram showing future in demand



Estimated projections for number of adults with learning disabilities (by severity) aged 65yrs and over, in Buckinghamshire.

Source Planning4Care 2010

The population of older people (65yrs+) with learning disabilities in Buckinghamshire, is projected to increase over the next 20years

Older people with learning disabilities and those with profound and multiple difficulties will require complex long term case management support.